DOCUMENT RESUME

ED 115 021 EC 080 418

TITLE MR74: A Friend in Washington.
INSTITUTION President's Committee on Mental Retardation, Washington, D.C.
PUB DATE Jun 75
NOTE 45p.
AVAILABLE FROM President's Committee on Mental Retardation, Washington, D.C. 20201

EDRS PRICE MF-$0.76 HC-$1.95 Plus Postage
DESCRIPTORS Exceptional Child Services; *Mentally Handicapped; *Organizations (Groups); Trend Analysis
IDENTIFIERS *Presidents Committee on Mental Retardation

ABSTRACT

Described in the report are the actions taken in 1974 by the President's Committee on Mental Retardation (PCMR). Included are reviews of presidential statements regarding the retarded and summaries of committee conferences (such as the conference on early intervention). Considered is PCMR's involvement in the following areas: administrative manpower, advocacy, consumer information, deinstitutionalization, education, employment, energy and the economy, federal programs, housing, international affairs, legal rights, legislation, the mentally retarded offender, prevention, public information, recreation, supplemental security income, technical assistance and liaison, transportation, youth affairs, and nontraditional approaches. Covered in a final section are suggestions derived from regional PCMR forums. (CL)

****
* Documents acquired by ERIC include many informal unpublished *
* materials not available from other sources. ERIC makes every effort *
* to obtain the best copy available. Nevertheless, items of marginal *
* reproducibility are often encountered and this affects the quality *
* of the microfiche and hardcopy reproductions ERIC makes available *
* via the ERIC Document Reproduction Service (EDRS). EDRS is not *
* responsible for the quality of the original document. Reproductions *
* supplied by EDRS are the best that can be made from the original. *
****

ED115021

U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION
THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

EC080418

PCMR

The President
The White House
Washington, D.C.

Dear Mr. President:

It is my pleasure to transmit to you the eighth annual report of The President's Committee on Mental Retardation, MR 74: A Friend in Washington.

The report describes the actions taken by the Committee throughout the calendar year 1974, in preparation for the forthcoming major report to you and to the people of this nation, as part of the Bicentennial celebration.

As this report indicates, however, PCMR also channelled its efforts toward addressing such issues as the energy crisis, inflation, health insurance, and administrative manpower, as they affect mentally retarded persons.

Your encouragement and support, Mr. President, are an inspiration to this Committee. We hope that the actions reported in this publication will further the continuing progress in the mental retardation field, and will justify the trust you have placed in us.

Faithfully yours,

Caspar W. Weinberger
Chairman

N. Lorraine Beebe

(Mrs.) N. Lorraine Beebe
Vice Chairman

The President's Committee on Mental Retardation has three main goals:

(1) To reduce the occurrence of disability from mental retardation;

(2) To promote humane services that will enable retarded persons to achieve their potential in the most normal, unrestrictive setting possible;

(3) To help retarded persons achieve the rights of full citizenship and public acceptance.

The President's Committee on Mental Retardation, Washington, D.C. 20201

DHEW PUBLICATION NO. (OHD) 75-21010
June, 1975

Library of Congress Catalogue No. 67–62450

FOREWORD

The bureaucratic haze that hovers over Washington sometimes tends to obscure the view as the States try to get a picture of what is happening there.

On the other hand, Washington's wide-angle vision of the rest of the nation can be so broad as to miss the details that make up the true picture.

This distorted image on both sides is especially applicable in the field of mental retardation, since mental retardation programs are spread throughout the agencies in Washington.

Is anybody there? Is anybody listening? Does anybody care?

The 21 citizen members of the President's Committee on Mental Retardation are appointed by the President precisely so that somebody will be there, in that focal spot, to provide two-way communication between the President and the people, Washington and the States, consumer and provider of services, public and private interests.

PCMR is there to listen, to watch, to advise. And to care.

For the millions of retarded persons in this country, PCMR is a friend in Washington.

This report is a condensed picture of one year in the life of PCMR, and how it performs its duties as defined in the Executive Order.

Results are not always apparent, nor dramatic. PCMR is a catalyst, a connector of people and ideas, a stimulator, a planter of seeds of progress. The end result is often a concerted effort of public and private action, gradually taking shape, nursed and nurtured until its time has come. PCMR's role is usually in the background, unlabeled when the final returns are in. That is as it should be.

A sample of how the liaison works; PCMR becomes aware, through its contacts, correspondence and observation, of a problem in the mental retardation field. Key people are asked to meet with a PCMR task force. The group explores the subject from a number of vantage points.

Then PCMR may ask a staff member or consultant to prepare a report on the problem. Staff and Committee members may make site visits, conduct interviews, read further on the situation, then make conclusions, after conferring with a variety of experts, to supplement the expertise of the Committee itself.

The discussion of the problem and possible solutions are incorporated in speeches, publications, perhaps radio and TV announcements done by PCMR. The problem may be discussed in meetings with the President, Cabinet members, agency officials and legislators.

Sometimes it takes years for concrete results, but gradually, the pieces fall into place.

A class action suit may be brought —often with PCMR publications used

as exhibits supporting the action.

A voluntary agency may move in a direction suggested by PCMR.

A new piece of legislation may reflect a concept PCMR has promoted.

A Federal agency may incorporate new requirements in its regulations.

A school board may develop a new program, often using PCMR publications to lend support and prestige in convincing board members.

Colleges and universities may develop new curricula, incorporating a new approach to the problem, or use PCMR ideas and publications as subjects for lectures or as textbooks.

By this time, the action that PCMR has instigated is moving ahead under its own steam. But the Committee has simply been performing its role as defined by the Executive Order from the President:

. . . to advise him on what is being done for retarded people;

. . . to recommend Federal action where needed;

. . . to promote coordination and cooperation among public and private agencies;

. . . to stimulate individual and group action;

. . . and to promote public understanding of mentally retarded people and their problems.

A FRIEND IN WASHINGTON

PCMR's year doesn't begin on January 1, nor end on December 31. The time frame is geared to what has been started in the past, what is current, and what will develop in the future, with the Committee attempting to be not just ready for what comes, but out ahead with new developments.

Many of the events in this report take place midstream in a movement encouraged by the Committee many years earlier, and just now gathering momentum. Community services and deinstitutionalization are an example.

The legal rights issue, on the other hand, may appear to be a fresh flame, setting fire to the status quo, burning away old concepts and established injustice. In truth, the issue has been smouldering for years. The class action suits, the individual court cases, the voluntary compliance with the law in many states to avoid legal action are relatively new on the mental retardation scene. But they are due to the spontaneous combustion of volatile situations. PCMR and many other public and private agencies, individual consumer representatives and public interest attorneys have been feeding the flames of a cleansing justice for close to a decade.

In 1974 there were no spectacular breakthroughs in the field of prevention of mental retardation, such as the earlier development of rubella vaccine, for example. But PCMR did co-sponsor a conference on early intervention that introduced new relationships between the developing structure of the human brain and the environment, and between parent and child and among parent/child/professional. It is such material that opens new horizons and cross fertilizes ideas that had previously

generated questions without answers. Such communication opens up new ways of thinking about human development.

YEAR'S HIGHLIGHTS

A great deal of the Committee's activities in the past year have been devoted to the preparation of a major report to the President and to the people, reviewing the past, documenting the present, and looking to the future as it leads through the last quarter of the century to the year 2000.

The first publication in the report's *Century of Decision* series was in preparation in 1974. Titled *Mental Retardation: The Known and the Unknown*, it is a fact book on mental retardation.

Preparation of the major report, to be completed by the end of 1975, has not diverted PCMR's attention from immediate problems; rather, as immediate problems were dealt with, they were incorporated in the material for the report.

Major Committee activities of 1974, accomplished to fulfill long-range needs of retarded people and the short-term goal of preparation of a major report to the President, include:

(1) An analysis of the "state of the art" from the beginning of this century, with particular emphasis on the past decade;

(2) A series of regional forums to hear from the people concerning the trends, issues, problems and progress in the field;

(3) A series of reports from States, national and international organizations reflecting major developments and policy;

(4) A dialogue with Federal agencies and Departments;

(5) The assistance of "futurists" in forecasting the shape of society in the year 2000 as a basis for recommending goals related to prevention, humane services, full citizenship, and public awareness.

In addition, the Committee co-sponsored, with the Association for Early Childhood Education International, a conference on Early Intervention With High-Risk Infants and Young Children (see p. . .). And there was much activity involved in planning for the Second Pan American Congress on Mental Retardation, to be held in Panama in August 1975, and co-sponsored by PCMR.

Each year the Committee meets quarterly, but throughout the year there are a great many task force meetings, plus numerous meetings with representatives of both Government and private agencies, attended by specific PCMR members, consultants and staff.

While the bulk of Committee work is transacted between the quarterly meetings, these regularly scheduled plenary sessions provide an opportunity to coordinate task force actions, as well as offering a forum for invited experts to report on the latest developments in a wide range of subjects relating to mental retardation. Members then vote on action to be taken.

The Steering Committee meets prior to each full Committee meeting.

Although each Committee meeting is different from the others, the following excerpts from the session of March 29–30, 1974 are presented as a "sample."

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION
March 29-30, 1974

AGENDA

Friday, March 29

9:00 a.m.	Opening Remarks and Introductions ..... Mrs. Beebe
9:10 a.m.	Statement by Vice Chairman on Steering Committee Activities and Progress ..... Mrs. Beebe
9:30 a.m.	Executive Director's Report ..... Mr. Krause Status of Programs on Staff Related Activities Budgetary and Fiscal Issues
10:30 a.m.	Discussion on the status of Federal programs
11:00 a.m.	Presentation on the National Health Insurance Plans ..... Dr. Peter Fox
12:00 noon	Lunch
1:30 p.m.	Projected Major Report to the President ..... Dr. Cobb Policy Issues and Proposals Primary Reports Subsidiary Reports Logistics Production Timetable Budget Plans for Distribution and Follow-up
4:30 p.m.	Public Information ..... Mr. Ferrara International Activities ..... Mrs. Beach
5:30 p.m.	Adjournment
Evening	Work Group Sessions

Saturday, March 30

9:00 a.m.	NARC's Activities and Projections ..... Mr. Marion P. Smith Views on Institutional and Community Living ... Mr. Peter Smith
10:30 a.m.	Policy Position on Deinstitutionalization Dr. Richard Scheerenberger Dental Care and Preventive Services ..... Dr. Arthur Nowak
1:00 p.m.	Discussion of Future Meetings
1:30 p.m.	Adjournment

The meeting was preceded by a session on March 18 with PCMR chairman Caspar Weinberger and selected members of the Committee and staff. They discussed the projected major report to the President, which the Chairman enthusiastically supported, and the question of the Executive Order, then pending the President's signature.

On March 28, the day before the first full Committee meeting of 1974, the President signed a new Executive Order, giving renewed life to the Committee, and expanding its role.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

Executive Order 11776, March 28, 1974

CONTINUING THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION AND BROADENING ITS MEMBERSHIP AND RESPONSIBILITIES

The President's Committee on Mental Retardation, established by Executive Order No. 11280 on May 11, 1966, has mobilized national planning and carried out basic programs in the field of mental retardation. National goals have been established to reduce the occurrence of mental retardation by one-half before the end of the century and to return one-third of the people in mental institutions to useful lives in their communities. The achievement of these goals will require the most effective possible use of public and private resources.

Our country has become increasingly aware in recent years of the need to assure those who are retarded their full status as citizens under the law, and of the continuing need to mobilize the support of the general public and of specialized professional and volunteer groups for mental retardation activities. We also know that we must constantly evaluate existing programs to determine their adequacy and must continually consider a broad range of proposals for new mental retardation activities.

NOW, THEREFORE, by virtue of the authority vested in me as President of the United States, it is hereby ordered as follows:

SECTION 1. *Committee continued and responsibilities expanded.* The President's Committee on Mental Retardation (hereinafter referred to as the Committee), with expanded membership and expanded responsibilities, is hereby continued in operation.

SEC. 2. *Composition of Committee.* The Committee shall be composed of the following members:

(1) The Secretary of Health, Education, and Welfare, who shall be the Chairman of the Committee.

(2) The Attorney General.

(3) The Secretary of Labor.

(4) The Secretary of Housing and Urban Development.

(5) The Director of the Office of Economic Opportunity.

(6) The Director of ACTION.

(7) Not more than twenty-one other members who shall be appointed to the Committee by the President. These persons may be employed in either the public or the private sectors and may include specialists in medicine and other healing arts, human development, special education, law, and employment problems, as well as members of foundations and other private organizations active in the mental retardation field. Except as the President may from time to time otherwise direct, appointees under this paragraph shall have three-year terms, except that an appointment made to fill a vacancy occurring before the expiration of a term shall be made for the balance of the unexpired term.

SEC. 3. *Functions of the Committee.* (a) The Committee shall provide such advice and assistance in the area of mental retardation as the President or Secretary of the Department of Health, Education, and Welfare may request and particularly shall advise with respect to the following areas:

(1) evaluation of the adequacy of the national effort to combat mental retardation;

(2) identification of the potential of various Federal programs for achieving Presidential goals in mental retardation;

Circling the President at the signing of Executive Order 11776, continuing and expanding PCMR, were, l. to r., PCMR members Ralph Ferrara, Melvin Heckt, Dr. Cecil Jacobson, Robert Collier; former PCMR vice-chairman Rep. Clair Burgener, Chairman Caspar Weinberger, Secretary of Labor Brennan, ex officio member of the Committee; members Dr. Henry Cobb, William B. Robertson, James Juliana, Michael Gardner, and Executive Director Fred Krause.

(3) provision of adequate liaison between Federal activities and related activities of State and local governments, foundations, and other private organizations; and

(4) development and dissemination of such information as will tend to reduce the incidence of retardation and ameliorate its effects.

(b) The Committee shall make an annual report to the President concerning mental retardation. Such additional reports or recommendations may be made as the President may require or as the Committee may deem appropriate.

SEC. 4. *Cooperation by other agencies.* To assist the Committee in providing advice to the President, Federal departments and agencies requested to do so by the Committee shall designate liaison officers with the Committee. Such officers shall, on request by the Committee, and to the extent permitted by law, provide it with information on department and agency programs which do contribute to or which could contribute to achievement of the President's goals in the field of mental retardation.

SEC. 5. *Administrative arrangements.* (a) The office of the Secretary of the Department of Health, Education, and Welfare shall, to the extent permitted by law, provide the Committee with necessary staff, administrative services, and facilities.

(b) Each member of the Committee, except any member who then receives other compensation from the United States, may receive compensation for each day he or she is engaged upon the work of the Committee, as authorized by law (5 U.S.C. 3109), and may also receive travel expenses, including per diem in lieu of subsistence, as authorized by law (5 U.S.C. 5703) for persons in the Government service employed intermittently.

(c) The Secretary of Health, Education, and Welfare shall perform such other functions with respect to the Committee as may be required by the provisions of the Federal Advisory Committee Act (5 U.S.C. App. I; 86 Stat. 770).

SEC. 6. *Construction.* Nothing in this order shall be construed as subjecting any Federal agency, or any function vested by law in, or assigned pursuant to law to, any Federal agency, to the authority of the Committee or as abrogating or restricting any such function in any manner.

SEC. 7. Executive Order No. 11280 of May 11, 1966, is hereby superseded.

Richard Nixon

The White House,
March 28, 1974.

After full discussion of the implications of the new Executive Order, the Committee heard a presentation by Dr. Peter [illegible], division of Health Analysis, HEW, on the new proposed Health Security Act of the Administration.

One of the principles of the proposal, he said, is that a low-income person and a high-income person are covered for the same services, but the low-income person does not face the same level of deductibles and co-insurance.

Some Committee members expressed concern about how mentally retarded persons now under Medicaid benefits would fare in the plan.

The Committee then heard a report from Marion Smith, President of the National Association for Retarded Citizens, outlining NARC's five-year plan. Following is an excerpt.

MR. MARION SMITH: "From painting the images of the future we see:

"One, increased implementation of prevention strategies and discovery of new forms of prevention to significantly reduce the incidence of mental retardation.

"Second, increased applications of ameliorative techniques and improvements in technology to enhance the level of functioning of all mentally retarded persons and decrease the prevalence of mental retardation.

"Third, all mentally retarded persons being given the opportunity to attain or retain their optimum level of development.

"Fourth, all mentally retarded persons living in conditions most conducive to their optimum level of development.

"Fifth, mentally retarded persons accepted by the public as equal and participating members of society. And mentally retarded persons in control of their own lives to the greatest degree compatible with individual conformity with cultural standards and individual happenings."

In introducing the next speaker, PCMR member Louise Ravenel said: "Peter Smith singlehandedly convinced the thousands of delegates at the NARC Convention at Anaheim, California, to change the name of the National Association for Retarded Children to National Association for Retarded Citizens.

"Peter lived for 33½ years in an institution for retarded people, and is now living and working successfully in the community. He is a member of the Board of the Minnesota ARC. His roommate, James Kinney, who is also with us, lived in an institution for 20 years."

MR. PETER SMITH: "I was put in an institution in 1936, and in that time we were all put together like a bunch of animals.

"We had to march in to the dining room, holding hands. And we couldn't talk during the meals. If we were being punished we had to stand up and eat.

"We ate out of old tin plates, and had tin spoons, tin cups. We got milk once a day for breakfast for our cereal. We never had any fruit or vegetables.

"We had a good education. The reason most of the patients were there wasn't because they were retarded. Maybe they couldn't get along on the outside or their parents didn't want them. So they shoved them in the institution.

"In 1950, I think it was, NARC and the Minnesota Association for Retarded Children started improving the life of the institution. They cut down the population and they started to have resident councils.

"During a resident council meeting I said, 'Why do we have to be called patients? We're not in the hospital. Why can't we be called residents?

"So they voted to change the name to residents.

"If we were caught talking to a girl, we were punished. We had to stand in the corner. We had to lay on the floor with our nose on the floor.

"And we had to take real cold baths when we were doing things wrong. We all had to go to bed at the same time. We all had to bathe at the same time. We all stood naked in the bathroom, and sometimes it was so cold in there.

"Now residents change their clothes and bathe when they want to. At that time we could only change our clothes and bedding once a week.

"We all had a work program. I was a work supervisor for a 111-man dormitory. I'd see the floor was clean, the toilets were clean. I took a scrub brush between my toes and scrubbed toilets just like the rest did.

"If we were out of hand, we had to clean toilets for 12 hours a day.

"I got ten cents a day for my work.

* Excerpted.

"Finally in 1950 I heared that there was going to be a new department of rehabilitation and recreation. So I talked to my technician and asked him if I could work for them. So he said, 'What can you do? You can't do anything because you're crippled up.'

"I said, 'You got to give me a chance so I can prove what I can do, not what you say I can do.'

"So in September I got the job. I answered phones and delivered mail. I took the phone off with my chin and laid it down, put my ear up to it to listen.

"And I swept. I hold the broom under my chin and sweep.

"One day I was sitting by a typewriter, and I said, 'Now, if I can learn how to type, maybe I will be busier.' So I got me a piece of wood about 12 or 13 inches long. I held that in my mouth and I started pecking on the typewriter. I kept it up day after day until I learned where the keys were.

"Now I have a typewriter with a little mouthpiece. It has a little stick on it with a rubber eraser, and I type like that. Nothing to it.

"In about 1968, a new social worker asked me, 'What are you doing here?'

"And I said, 'I'm a patient here. I'm a catatonic schizophrenia paranoid.' I was kidding her. I have been called that.

"Well, Mrs. Flanagan told me, 'You're not mentally retarded. You're not mentally ill or feebleminded or paranoid.' She said, 'You find yourself a good friend, and I'm going to see that you get out of this institution.'

"So I told her about Jim and she said, 'Okay.' She put us on independent living, which is a building or room by itself at the institution. We went downtown or any place we wanted to.

"We stayed there for a year, and then got out of the institution in December of 1969. She told me, 'You find a place to live. I'm not going to help you.'

"We found a rundown place that we rented for about a year. Then I found a better place and we moved and are still living there. We have a three-bedroom apartment. Jim does the cooking and the housework.

"For about a week after I got out it was a difficult time for me. I had to meet the bus, learn to get myself out of bed, get to work on time. It was really difficult. But we managed it.

"For a week we didn't wash our clothes because we didn't have the money. But after we got our first checks we started putting money in the bank and then we started getting better furniture.

"I'm very proud of being out.

"I am working at the institution in the office and Jim is working in the main kitchen as a dishwasher. And we get a salary and fringe benefits. We joined the union.

"This is something I fought for since I have been there—to join the union.

"There's no problem in the community. People are willing to help the handicapped. That's what made me proud to be out. There's not all mean people in the world.

"Sometimes I don't even sleep at night because I think of the things that we should do to improve the institutions, the community homes and life for those who can't talk and those who can't speak and those who don't know what life is.

"But we cannot close institutions, because there are a lot of residents who do not want to leave them. Do they have a right to stay as well as to leave?

"Some of them that have been out say they want to move back. That's their constitutional right to go back to an institution.

"So we can't close the institutions. We can cut them down but not close them."

RENI PHOTOS

Mr. Peter Smith

RENI PHOTOS

James Kinney (1) is greeted by PCMR Executive Director Fred Krause. Vice Chairman Lorraine Beebe and NARC's Jim Wilson stand behind them in the receiving line at an NARC reception held for the Committee.

*MR. JAMES KINNEY: "I have been in three institutions, much different than Peter's. One was a lockup. You couldn't go outside. We didn't have television; all we had was phonograph music.

"My grandmother went to the Ohio court to get me out. She got me to Fairfield. When I looked at Fairfield I almost fainted. They had recreation, movies, dances, education, school.

"I didn't learn when I first went to an institution. I found out later my mother said I was dumb, I wasn't going to learn. I told my mother one day, 'I had no chance to learn.' I said, 'Do you really want to take me to school, learn me something? I would have went and I would have learned.' But cake and ice cream were not learning. I had cake and ice cream. That's all I saw.

"If I had an education book I would learn. I wouldn't care if it took me a hundred years to learn, I would be learning.

"Kids now have got it a lot better than we had. They got better education than we had.

"I didn't get out for the fun of it. I got out to show people what I could do, not show how retarded I am. I want to prove I can make a living.

"I know what you guys are doing. I never believed in PCMR before, but what you are doing is a miracle.

"Being on the Board of Directors of the Minnesota ARC is really something else. Thanks much to Peter. Not all of it, no. I give *me* thanks for helping *him*.

"I could have had no arms, no nothing. So I got something to be thankful for.

"When I see it, I'm just ready to bawl, but I don't cry. Because I think God made us all different.

"I wish you good luck in the future."

When the applause died down, NARC's Marion Smith asked Peter Smith if he would be available to testify on behalf of NARC before Congressional Committees. He agreed to do so.

Messrs. Peter Smith and James Kinney were made Special Advisors to PCMR.

* Excerpted.

Dr. Richard Scheerenberger, President of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, then discussed the superintendents' policy statement, then in preparation, and later published by PCMR. It was prepared as a result of a 1973 meeting, held with PCMR's assistance.

Dr. Scheerenberger talked with Committee members and staff about some of the problems in institutions. Questions were raised on whether or not Federal and State monies are reaching the people for whom they are intended. There was agreement on the importance of administrative training—a subject the Committee has been involved in for the past few years.

After further discussion, the Committee's next speaker was Dr. Arthur Nowak, President-elect of the Academy of Dentistry for the Handicapped. His subject was "Dental Health for the Mentally Retarded Citizen."

After describing how dental and gum problems develop, Dr. Nowak said that the average child on entering school has three decayed teeth. By age 15, the average child has 11 teeth that are decayed, missing, or filled.

"Dental Disease," he said, "is the most prevalent of all chronic diseases, dental or medical. Mentally retarded and other handicapped citizens find dental treatment more difficult to locate and purchase than any other single group of people."

He pointed out that physical well-being is a relatively neglected area in the field of retardation. The rewards for good behavior, he said, are often food and beverages which not only result in obesity, dental disease, dermatological problems and generally poor health, but also have little or no nutritional value.

"Thus, on the one hand," Dr. Nowak continued, "we are teaching good behavior. But on the other, we continue to contribute to their dehumanization."

He cited the fact that dental care has a very low priority in many if not most facilities. All too often dental care means tooth removal, "crisis dentistry instead of prevertive dentistry."

"We feel that the time is now right for those advocacy groups, agencies, institutions and legislative committees to join with dentistry in the development of a comprehensive oral health maintenance program that will be capable of reducing and possibly even eliminating the effects of dental disease in the mentally retarded citizen," he concluded.

Dr. Nowak had earlier pointed out that the Academy of Dentistry for the Handicapped has grown from a membership in the late 1960s of approximately 80 members to over 400.

Mr. Marion Smith requested the list of members so that NARC could contact them, and put them in touch with State and local units to establish liaison.

PCMR member Bob Mallas suggested that Mr. Smith supply Dr. Nowak with names of dentists who are parents of retarded children, for possible recruitment to membership in the Academy.

Dr. Nowak presented Committee members with copies of the Academy's publication *Campaign of Concern* on dentistry for handicapped persons.

And the meeting was adjourned.

(Dr. Nowak was later made a PCMR Consultant.)

LARRY ROBIN

PCMR ACTIVITIES

Outstanding occasions for the Committee were the meetings with the President at the White House. The group met with President Richard Nixon on March 28, when he issued the new Executive Order (see page 4) and with President Gerald Ford on October 11, at which time he released the following statement:

THE WHITE HOUSE

STATEMENT BY THE PRESIDENT

Three years ago, America committed itself to cutting the rate of mental retardation in half by the end of the century. That is a notable goal, worthy of a great nation, and today in meeting with the President's Committee on Mental Retardation, I have renewed our commitment to that goal.

The problem of mental retardation deserves our attention not only for the sake of the more than six million afflicted Americans and their families, but for all of us. The majority of retarded citizens can become productive members of society.

There are three important points about mental retardation that must be understood:

One, with appropriate training, retarded people are capable of continuing development in normal community settings. Primarily through its housing agencies, the Federal Government will help retarded adults obtain suitable homes. But the real help must come from the local level.

Two, corrective measures in early childhood can reduce the severity of a handicap. Young children should be screened for handicaps and, when found, they should be corrected.

Three, since we know some of the causes of mental retardation, we know some ways to prevent it. Biomedical research may be helpful in extending this knowledge.

At present rates, some four million of our children expected to be born by the year 2000 will be retarded or become retarded. The members of the committee have advised me that it is realistic to believe that the number can be reduced by half, and I urge all segments of our society to do their part in achieving this objective.

To attain this goal, every prospective mother should have available to her good prenatal care, including the most current techniques of fetal diagnosis and genetic counseling where necessary. She should know the kind of diet which will promote proper growth of the fetus. Good care for mother and child should continue postnatally, with special attention for premature infants. Infants and young children should be screened at appropriate intervals for hearing, visual and other defects which could impede their learning ability, so that the defects may be corrected before the child falls far behind.

A healthy environment and an adequate, balanced diet are especially im-

portant throughout the younger years, as is vaccination against rubella and other diseases.

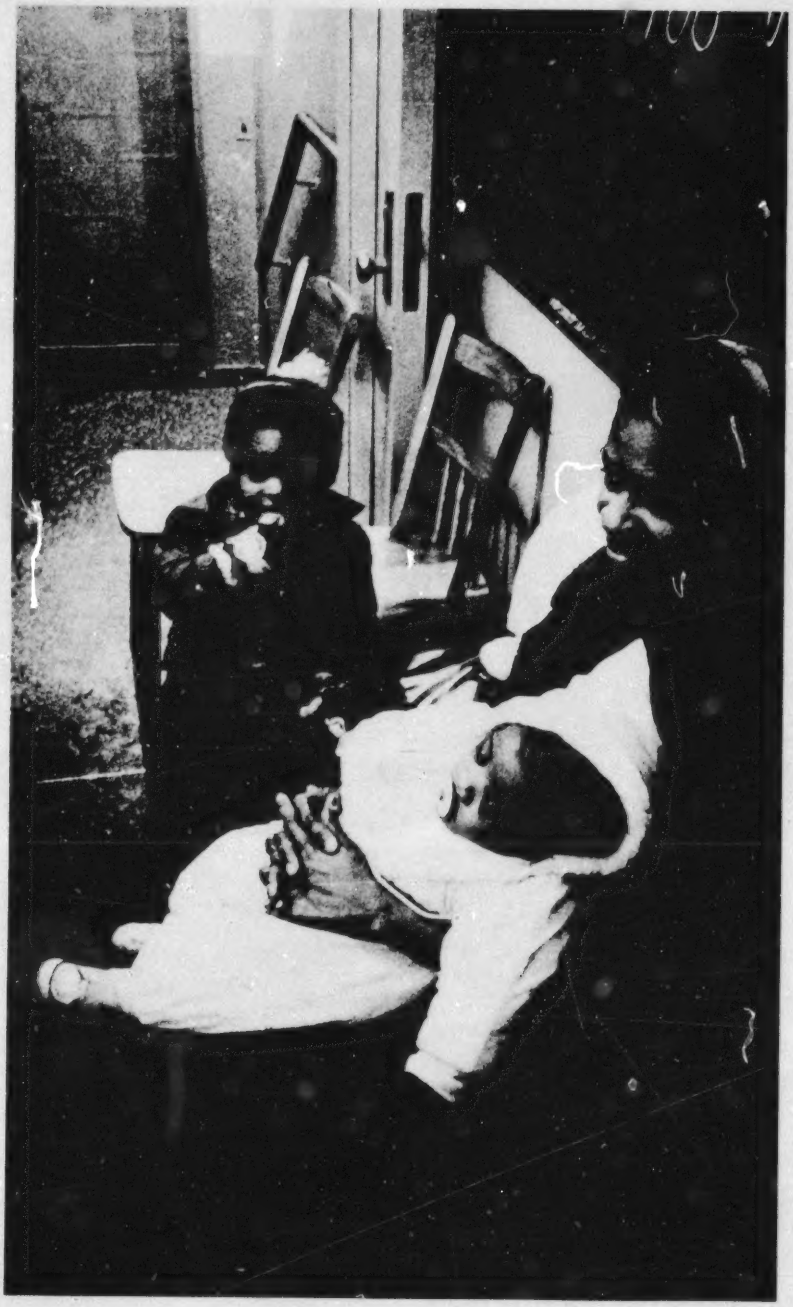
Our school systems must be strengthened, so that they can provide the appropriate education which both the law and our conscience say may not be denied to retarded or otherwise handicapped children. By appropriate education, I mean training in academic, vocational and social skills which will enable these children to live up to their highest potential. And let us never underestimate how high that potential is.

In the last few years, great progress has been made in winning legal recognition for the rights of retarded citizens—not only the right to education, but the right not to be confined in an institution without habilitative treatment, the right to be paid for work done, and other rights that belong to all citizens.

I urge employers to consider the very real job capabilities of retarded persons and to use the U.S. Employment Service to the fullest possible extent in hiring retarded persons. If we forget stereotypes and look at retarded people as people, we will recognize what so many of them have already proved—that they can do hundreds of different jobs reliably and well.

There is urgent need to chart a concerted effort to minimize the occurrence of retardation, and to assure humane services and full citizenship for those who are retarded. I encourage this Committee to pursue to completion its report on the directions that effort should take over the next quarter century.

Finally, I call upon all Americans to become more familiar with the problems of retardation, and the potentials of retarded people. With our understanding, they will thrive. With our love, they will flower.



162

Because of the alarming drop in the number of immunizations against infectious diseases, the Committee, while meeting with the President, requested that the President issue a Proclamation calling attention to the fact, and encouraging action. The Proclamation was coordinated with other national immunization efforts that have such impact on prevention of mental retardation as well as other disabilities.

THE WHITE HOUSE

IMMUNIZATION ACTION WEEK, 1974

BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

This Nation has always been committed to fostering the health of its people, and particularly of its children. Immunization against disease has been an exciting chapter in that effort. The United States can take pride in the dedicated research which has produced safe and effective vaccines against polio, measles, rubella, and other childhood diseases.

Cooperation by the medical profession and public health organizations in distributing these vaccines to children has achieved dramatic reductions in diseases which can kill, cripple, or cause birth defects, including mental retardation. Because of their tragic consequences, we dare not let down our guard against a resurgence of these diseases.

The President's Committee on Mental Retardation has brought to my attention an alarming decline of immunity levels among pre-school children. Last year more than 40 percent of these children were unprotected against either polio, measles, rubella, diphtheria, pertussis, or tetanus. On polio, for example, the Department of Health, Education, and Welfare Center for Disease Control reports that immunization levels dropped from 79 percent in 1963 to 60 percent in 1973.

Our children are America's future. Let us make that future a healthy one, for their sake and the Nation's sake.

NOW, THEREFORE, I, GERALD R. FORD, President of the United States of America, do hereby proclaim the week beginning October 20, 1974, as "Immunization Action Week," and call upon all parents, educators, and medical personnel to exert renewed efforts during this week and throughout the year to immunize every American child against diseases for which vaccines are available.

IN WITNESS WHEREOF, I have hereunto set my hand this twenty first day of October, in the year of our Lord nineteen hundred seventy-four, and of the Independence of the United States of America the one hundred ninety-ninth.

GERALD R. FORD

RUBELLA IMMUNIZATION
Age 1–4 years

Total 14 million

56.9%	55.6%	59.8%
1972	1973	1974

Source: Center for Disease Control, Atlanta, Georgia.

At the request of Mrs. Gerald Ford, PCMR organized and coordinated a special Christmas tour of the White House for over 1,500 retarded children and adults of the D.C. area. The tour was held Friday, December 20, at which time the White House was resplendent with Christmas decorations.

"I have often felt that the high drop-out rates in family planning clinics was because some individuals were not able to understand the educational material. At least some were probably mildly mentally retarded."

Naomi Gray
Naomi Gray Associates
At San Francisco Forum

"In our area there are families with retarded children, 18 or 19 years old, who are not involved in any programs, who have never been to school because of the lack of information. One of the primary problems is the language barrier."

Virginia Lopez
Community Outreach Worker
Project Impact
San Diego, Calif.
At San Francisco Forum

"There is a need to meet the client's needs wherever that may be. The institution can no longer be looked upon as an institution apart from everything else. It has to become a resource center to deal with an open door policy with problems in the community, with training of the workers, providing follow-along where there's a need, working together with one thing in mind—the client's need."

Dr. Joseph Garneau
Governor's Executive Budget Officer
The State of Colorado
At Denver Forum

The Committee's interests cover every area of the diverse mental retardation field. Following is an indication of range of activities and the Committee's involvement. Many of the items represent intermediate stages of a long-term commitment in that area.

ADMINISTRATIVE MANPOWER

At the quarterly meeting of the Developmental Disabilities Advisory Council, PCMR reported on the need for trained administrators of mental retardation programs. The Committee submitted a proposal to Chairman Weinberger in his double capacity as PCMR Chairman and HEW Secretary.

We reviewed with the Association of University Programs in Health Administration the plans of its consortium with the Association of Mental Health Administrators and the American Psychiatric Association to develop curricula for preparation of administrators of mental health programs.

PCMR members spoke to several groups on the need for such training of administrators of agencies serving mentally retarded and developmentally disabled persons.

ADVOCACY

The Committee sponsored a brainstorming and planning session on advocacy, attended by officials of ten agencies, Governmental and voluntary.

The result was (1) formation of a consortium of organizations to develop a fact-finding, research type project to determine what advocacy in any of its forms entails for retarded people; and (2) initial planning for a pilot regional conference on advocacy in 1975 in Pennsylvania.

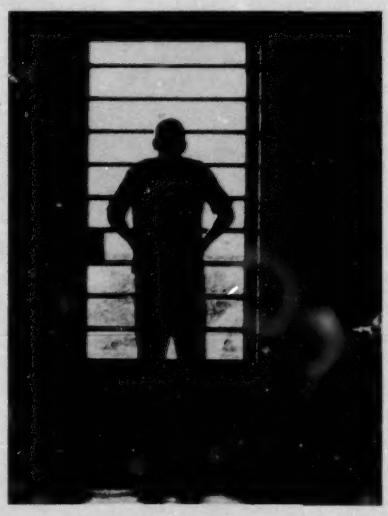
CONSUMER INFORMATION

We investigated possible models for improved consumer information systems on mental retardation, including: "Closer Look" of the Bureau of Education for the Handicapped, Council for Exceptional Children, United Way of America, American Red Cross, Consortium on Early Childbearing, City Hall Complaint Service of the District of Columbia, Planned Parenthood World Federation, the New Jersey SCOPE system, and Computer Assisted Placement Service of Medical Datamation.

Following visits, PCMR analyzed the place of consumer information in present information systems, and assisted the Information and Resources Clearinghouse of Office for Handicapped Individuals in designing the scope of a project proposal to develop such a system to include consumer information.

In its front-line service to the consumer, the PCMR correspondence section responded to 8,230 written requests for assistance, information, publications, and/or referrals. Total incoming correspondence to PCMR topped 12,000 for the year.

That is an average of close to 50 requests for some kind of assistance every working day of 1974.



LARRY ROBIN

PRIMARY REASONS FOR READMISSIONS DURING FY 73-74 AS REPORTED BY 135 RESIDENTIAL FACILITIES

Reason	n	% *
Community rejection	31	22
Lack of community services:	70	50
Activity centers & sheltered workshops	(12)	(9)
Advocacy services	(1)	(1)
Behavior management programs	(16)	(12)
Comprehensive services	(23)	(17)
Counselling	(5)	(4)
Day care	(11)	(8)
Education/Training	(13)	(9)
Employment	(9)	(6)
Family support	(2)	(1)
Follow-along services	(39)	(28)
Living accommodations	(27)	(19)
Medical services	(21)	(15)
Parent training	(4)	(3)
Failure to adjust	64	46
Family:	24	17
Could not adjust	(21)	(15)
Moved	(3)	(2)

*Exceeds 100% because more than one reason given.

COMMUNITY PLACEMENTS AS REPORTED BY 115 RESIDENTIAL FACILITIES

Placement	n	%
Independent living	137	1.5
Work placement	145	1.6
Parent's (or guardian's) home	2448	27.0
Other relative's home	261	2.9
Foster home	1182	13.1
Boarding home	51	.6
Group home	2227	24.6
ICF facility	501	5.5
Rest or convalescent home	248	2.7
Nursing home	1386	15.3
Intensive (nursing) care facility	457	5.2
Total	9043	100

Source: Current Trends and Status of Public Residential Services for the Mentally Retarded. National Association of Superintendents of Public Residential Facilities for the Mentally Retarded. PCMR, 1974.

DEINSTITUTIONALIZATION

PCMR convened a meeting of the leaders of the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded to develop a position paper on deinstitutionalization and improvement of institutions.

The result was *Residential Programming: Position Statements by the NASPRF*, published by PCMR in 1974.

The staff analyzed essential standards for Intermediate Care Facilities-Mental Retardation (ICF-MR) regulations, and later participated in a review of draft guidelines designed to help States apply the ICF-MR standards.

PCMR arranged with the Mental Retardation Division of the American Psychological Association to make a study of current psychological research on deinstitutionalization.

The Committee initiated inter-departmental cooperation between the Department of Justice and HEW for suits bearing on quality of service in institutions.

Maine and Florida requested and received PCMR assistance in developing deinstitutionalization plans.

New Neighbors, a monograph on community living was published, and a casebook on existing community residential care alternatives was in preparation, to be published in early 1975. Its title: *People Live in Houses*.

There was a continuing effort to influence regulations, policies and practices of the Social Security Administration and the Social and Rehabilitation Service of HEW to cancel conflicting policies and improve program reinforcements so as to provide major inducements to retarded persons to move to the com-

"Fifteen to twenty percent of an agency's time is spent writing and rewriting regulations to comply with the last announcement in the Federal Register of another change on the Federal level. If we could take that 15–20% and use it to give service to the individual, we could make a lot of progress."

Carl D. Rodland
Director, Div. of Developmental Disabilities
N.D. Dept. of Health
At Denver Forum

"If we do not have a spread of high quality community residential and developmental programs, all we are participating in is a dumping operation out of institutions. It will not be tolerated by communities because they will be looking for an excuse not to have these people returned to the community."

Carlyle Storm
President, Md. ARC
At Philadelphia Forum

munity and become more self-sufficient.

PCMR formed a special ad hoc committee to initiate efforts to rationalize building codes and zoning regulations, so that they would be protective, but not restrictive.

PCMR assisted in a study done by the National Association of Superintendents of Public Residential Facilities, called *Current Trends and Status of Public Residential Services for the Mentally Retarded*. It shows an 8.9% reduction of institutional population between 1970 and 1974.

A meeting was held with the President of the NASPRF to discuss labor-management relations in institutions and their effect on deinstitutionalization. Since union contracts are negotiated at State level, superintendents of these facilities are concerned about their ability to handle union problems. The group considered as possible solutions: training in labor relations for superintendents, improved orientation of State administrators to institutional labor problems, and efforts to improve legal advocacy of individual residents of the facilities.

PCMR participated in a Nebraska conference on residential care alternatives, acted as consultant for Hawaii on community residential services, and provided technical assistance on deinstitutionalization to several other States.

Committee members voted to support continuation of the requirement that a facility be in substantial compliance with applicable standards for each part of the facility in order for that facility to receive accreditation. PCMR Executive Director conveyed the Committee's position to the Accreditation Council for Facilities for the Mentally Retarded at hearings held in Chicago in July.

The General Accounting Office staff met with PCMR staff to discuss GAO's proposed study of progress of deinstitutionalization and its effects on mentally retarded persons.

Arrangements were completed for an updating of PCMR's *Changing Patterns in Residential Care*, first published in 1969. It has had a major impact on changes in the mental retardation field.

EDUCATION

PCMR strongly supported:

A sustained role of Bureau of Education for the Handicapped in educational policy development;

Continuation of current effort to prepare special education teachers, especially in light of demands of right to education rulings by the courts;

Continuation by Congress of current levels of Federal financial support for local and State educational agencies serving handicapped children;

Study, experimentation and testing of alternatives prior to any changes in program leadership and funding for special education.

There were discussions with the Office of Child Development, HEW, on the percentage of retarded children in Headstart, and an analysis of proposed Headstart rules governing recruitment, enrollment and services to handicapped children, and special services such as early identification of problems and intervention.

PCMR provided an orientation to the Committee's role and goals to the School Psychologist Division of the American Psychological Association, which is concerned with maintaining standards and a professional role in new programs of early diagnosis and assessment of young children who may be retarded.

PCMR staff met with the Council of the Great City Schools, a coalition of 24 of the largest urban school districts in the U.S., to discuss educational reforms that will ensure quality and equality of educational opportunities.

"We have all the research available that shows that early childhood programs are beneficial for handicapped children. Why not recommend that every State be allowed to have early childhood programs Federally funded?"

Dr. Dan Payne
Assistant Commissioner
Program Development and Evaluation
Dept. of MH/MR, Virginia
At Philadelphia Forum

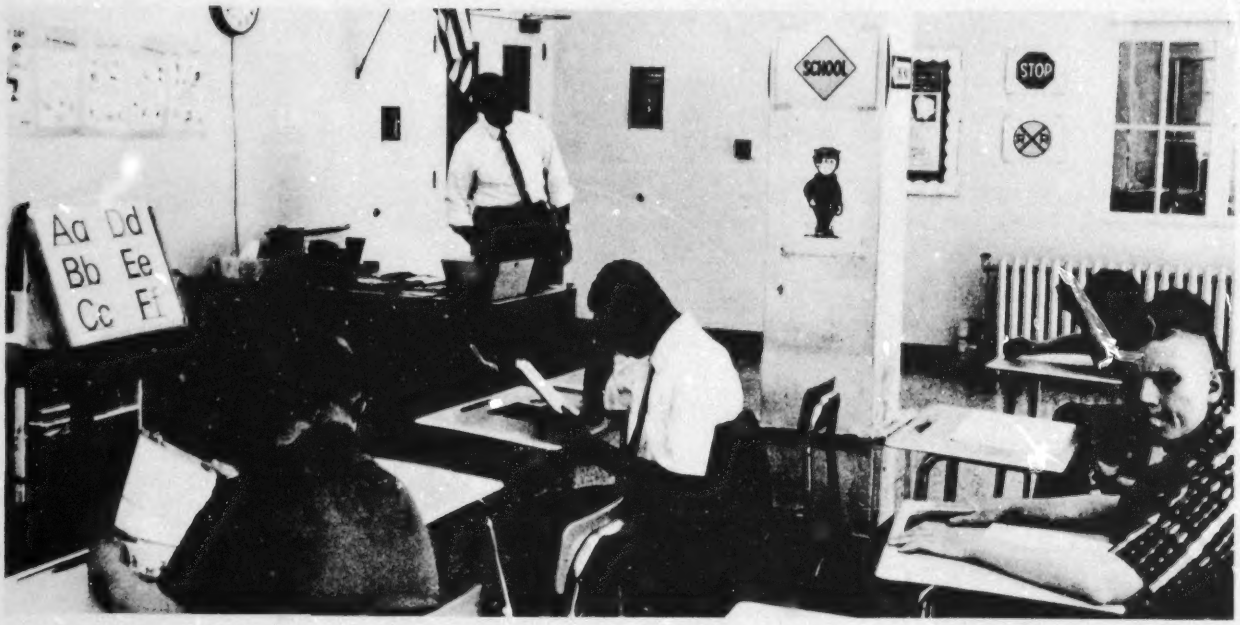
"The new challenge to higher education is to move into the field with their training. Medical schools could do this too—have the students work in programs for retarded people and see what is really going on. I would hope that higher education would also extend its resources and services to the workers, including parents and many helpers who would benefit from help and training."

Dr. Leo Cain
President, U. of Calif.
at Dominguez Hills
At Denver Forum

"When we spend money to help a handicapped child get an education, we are not just spending money; we are making an investment. We help that child become less dependent. . . . A failure to make that investment means that we force that child to be forever dependent on society, to become a ward of the State."

Hon. Richard S. Schweiker
Senator from the State of Pennsylvania
At the Philadelphia Forum

Senator Schweiker



ESTIMATED NUMBER OF HANDICAPPED CHILDREN SERVED AND UNSERVED BY TYPE OF HANDICAP

	1974-75 [a] SERVED (Projected)	1974-75 UN-SERVED	TOTAL HAND. CHILD. SERVED & UN-SERVED [b]	% INCI-DENCE	% SERVED	% UN-SERVED
TOTAL AGE 0-19	3,947,000	3,939,000	7,886,000		50%	50%
TOTAL AGE 6-19	3,687,000	3,062,000	6,699,000		55%	45%
TOTAL AGE 0-5	260,000	927,000	1,187,000		22%	78%
SPEECH IMPAIRED	1,850,000	443,000	2,293,000	3.5%	81%	19%
MENTALLY RETARDED	1,250,000	257,000	1,507,000	2.3%	83%	17%
LEARNING DISABILITY	235,000	1,731,000	1,966,000	3.0%	12%	88%
EMOTIONALLY DISTURBED	230,000	1,080,000	1,310,000	2.0%	18%	82%
CRIPPLED & OTHER HEALTH IMPAIRED	235,000	93,000	328,000	.5%	72%	28%
DEAF	35,000	14,000	49,000	.075%	71%	29%
HARD OF HEARING	60,000	268,000	328,000	.5%	18%	82%
VISUALLY HANDICAPPED	39,000	27,000	66,000	.1%	59%	41%
DEAF-BLIND & OTHER MULTI-HANDICAPPED	13,000	27,000	40,000	.06%	33%	67%

[a] Based on estimates from State education agencies for fall and winter, 1974-75.
[b] Based on estimates from national agencies and organizations and State and local directors of special education. Population figures to which incidence rates were applied are from the Bureau of the Census and reflect the population as of July 1, 1974.
Source: U.S. Office of Education/Bureau of Education for the Handicapped, March 1974.

EMPLOYMENT

At PCMR's request, there was a meeting with U.S Postal Service representatives, concerning dismissal of some retarded workers because of an interpretation of some policy statements issued by the Postal Service. In many instances, the workers were reinstated, through the cooperative efforts of the Postal Service and Postal Unions, with PCMR attempting to improve these lines of communication in order to strengthen employment opportunities for retarded persons.

When the Employment Division of the U.S. Department of Labor was preparing a new interviewing guide to be used by employment counselors seeking to place retarded individuals, PCMR acted as consultant.

PCMR participated in the annual meeting of the President's Committee on Employment of the Handicapped, which emphasized on-the-job placement, vocational training and employment programs.

The NARC subcommittee on vocational rehabilitation and employment met with PCMR to determine strategy for joint planning and services to the retarded adult.

The Executive Director of PCMR was on the advisory panel of the Department of Labor's Manpower Administration which is developing a handbook on the use of the basic skills of mentally retarded workers.

PCMR representatives also served on task forces on definition, attitudinal barriers, and job redesign of the Interdepartmental Committee on Handicapped Employees.

ENERGY AND THE ECONOMY

PCMR worked with the Federal Energy Office to get them to modify their proposal on fuel allocations to safeguard the welfare of retarded persons, especially those vulnerable to heating and transportation shortages.

The Committee issued a position statement on the hazards entailed, and coordinated a seven-State survey, conducted by voluntary advocacy organizations for the developmentally disabled, that indicated shortages and increasing costs of gasoline were the greatest concerns, and suggested

"Delivery of service is complicated in these western States by Federal funding that comes from so many departments and so many avenues that it requires a paid staff member to do nothing but find the money. That salary could better go to direct service."

Jane Lane
First V.P., Wyoming ARC
At Denver Forum

"We talk about umbrella agencies, but it always rains on the retarded."

Roland Queene
Director of Office of Mental Retardation, State of Virginia
At Philadelphia Forum

"Most of our revenue sharing monies, in North Dakota at least, have been spent for bricks and mortar, not for people programs."

Miss Claudette Janis
Rosebud Reservation, S.D.
At Denver Forum

means whereby facilities could qualify for priority allocations.

Two meetings of national voluntary and public organizations were convened to assess the fuel shortage problem and develop strategies for coping with it.

PCMR also contributed to the HEW position paper on the needs for special protection of poor and handicapped persons during the energy crisis.

The Committee and staff prepared material for HEW's contribution to the President's summit meeting on inflation by analyzing the impact of inflation on mentally retarded persons and their serving agencies.

FEDERAL PROGRAMS

At PCMR's request, 22 Federal agencies and departments submitted information on the relationship of their work to mentally retarded people. A liaison with each agency has been established in regard to minimum occurrence of disability in mental retardation, full citizenship, humane services and public awareness.

A report to the President on Federal activities will be prepared, updating the previous PCMR publication, *Federal Programs for the Retarded.*

HOUSING

PCMR representatives met with Housing and Urban Development's Assistant Secretary for the Aging and Handicapped to explore HUD's activities in developing housing and group home living for retarded persons.

They also discussed a recent proposal for establishing a national center to study housing for handicapped people.

Under PCMR auspices, an ad hoc committee met to study and act on codes, standards and zoning related to housing for people who are handicapped.

A staff member addressed the annual AAMD meeting on the cost-benefit and cost-effectiveness considerations of such housing, in light of fixed financial limits. He stressed creative thinking and the use of normalization principles.

A Committee representative chaired a session of the National Conference on Housing for the Handicapped in Houston, and spoke to the American

Planning for the Second Pan-American Congress on Mental Retardation are (l to r) PCMR members Ralph Ferrara and Marianna Beach; Eloisa Garcia de Lorenzo and Rafael Sajon of the Inter-American Children's Institute, Uruguay; and Dr. Will Beth Stephens, PCMR.

Institute of Architects' second regional conference and workshop on Designing for the Disabled.

INTERNATIONAL AFFAIRS

Several planning sessions centered around the Second Pan-American Congress on Mental Retardation to be held in Panama in August 1975. The first such conference was held in Puerto Rico ten years ago, as an outgrowth of the President's Panel on Mental Retardation.

To plan the Congress, PCMR has met with representatives of the State Dept., HEW's Office of International Affairs, The Organization of American States, Partners of the Americas, Panama and UNESCO, plus the co-sponsors, who, together with PCMR, are the Instituto Interamericano del Niño and the Instituto Panameño de Habilitación Especial.

In addition, preliminary planning was done on programs for training personnel in other countries, especially in developing countries, to work with retarded persons. Included in these plans is the projection of a system of an international exchange of information on mental retardation.

PCMR representatives participated in the International Conference on Special Education in Spain, the International League of Societies for the Handicapped Symposium on Mental Retardation in Brazil, the Caribbean Conference on Mental Retardation in Barbados, and the World Conference on Rehabilitation Medicine in Mexico City.

Visitors from Sweden, Poland, Korea, England and countries of South and Central America met with PCMR staff and members to discuss their programs and exchange ideas.

LEGAL RIGHTS

The Committee in 1974 conducted an all-points public information campaign on legal rights which included:

(1) A proclamation by the President of Legal Rights Week;

(2) A proclamation by Governors designating April as Legal Rights for Retarded Citizens Month;

(3) Distribution to radio stations of public service announcements and a recorded interview with the PCMR Work Group Chairman on Legal Rights;

(4) Distribution of an information kit to newspapers and regional and State offices of the Association for Retarded Citizens;

(5) Furnishing information used in developing a two-page article in *U.S. News and World Report;*

(6) Publication of *Silent Minority,* a popularly written report on PCMR's Legal Rights Conference of 1973;

(7) Released "A Little Slow," a film which dramatizes the legal rights problems of two young adults (Funded by BEH);*

(8) Helped edit a definitive book on the subject, *The Mentally Retarded Citizen and the Law* resulting from the 1973 Legal Rights Conference.**

"How good it is for people from different countries to work together. Then we have a different image of what an American is, because the image at the beginning is United Fruit and capital investment, machines and cold technology. We develop defenses. And then through such meetings as this, we see another type of American—absolutely different. . . . One of the best things I will take from here is the knowledge that you really care and understand."

Eloisa García de Lorenzo
Instituto Interamericano del Ninos
Montevideo, Uruguay
At PCMR's Early Intervention Conference

"There is a strong need for training in this field in our country. Most workers in these fields are not professionally trained and so, most institutions are unable to provide competent treatment services to the retarded."

Kim, Young Ja
Director,
Ministry of Health and Social Affairs
Republic of Korea
In a letter to PCMR

LARRY ROBIN

* The film may be borrowed without charge from Association-Sterling Films. Service will be expedited by writing to its nearest exchange rather than PCMR: *Exchanges:* 410 Great Road, Littleton, Mass. 01460; 600 Grand Ave., Ridgefield, N.J. 07657; 324 Delaware Ave., Oakmont, Pa. 15139; 5797 New Peachtree Rd., Atlanta, Ga. 30340; 512 Burlington Ave., La Grange, Ill. 60525; 6420 W. Lake St., Minneapolis, Minn. 55426; 8615 Directors Row, Dallas, Tex. 75247; 915 N.W. 19th Ave., Portland, Ore. 97209; 25358 Cypress Ave., Hayward, Cal. 94544; 7838 San Fernando Rd., Sun Valley, Calif. 91532. Prints may also be purchased at $58.25 each from Sales Branch, National Audio Visual Center (GSA), Washington, DC 20409.

** To be published in late summer, 1975. For information about availability, write:
The Free Press
A Division of MacMillan Publishing Co., Inc.
New York, N.Y. 10022

"Here is a dramatic illustration of the work of the Committee. PCMR's work with the Justice Department was of critical emotional and intellectual importance to this lawsuit's being filed within the last 30 days. To lawyers this is a landmark case. PCMR's conversations on the subject date back to early 1970, and from then on there has been ongoing work with the staff of the Civil Rights Division of the Department of Justice."

Lawrence Kane
Chairman, PCMR's Legal Rights Work Group
At PCMR Meeting

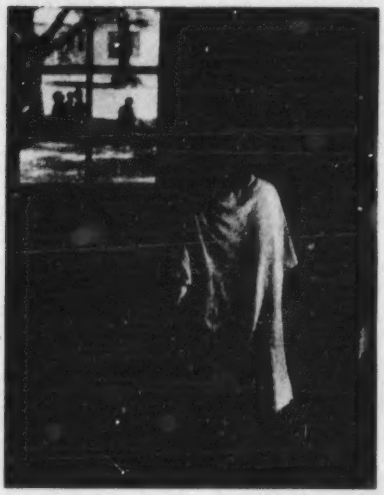
PCMR cooperated with the Dept. of Justice on the first Federal Government suit of its kind in the field, brought against the State of Maryland for deprivation of residents' rights in a State mental retardation institution.

Committee representatives worked with the HEW Assistant Secretary for Human Development and the Justice Department's Assistant Attorney General, Office of Civil Rights in the case.

A report on current court action in mental retardation is published periodically. Funded by PCMR and the Office of Child Development, it is titled *Mental Retardation and the Law.*

The Committee also directed preparation of a *Compendium on Litigation in Legal Rights of the Mentally Retarded.*

Additional activity in this area includes a concerted effort on legal and legislative matters with the National Center on Law and the Handicapped, Mental Health Law Project, Dept. of Justice's Office of Special Litigation, American Bar Association's Commission on the Mentally Disabled and other legal and legislative advocacy groups.



LARRY ROBIN

LEGISLATION

PCMR prepared an in-depth analysis of the Administration's Comprehensive Health Insurance Proposal, as it relates to mentally retarded people, and advised on legislative guidelines.

Staff wrote a position paper on the addition of learning disabilities to the Federal definition of Developmental Disabilities, with regard to new legislation.

Information was also provided in response to Congressional inquiries on the supplemental appropriation for the education of the handicapped.

The Committee had an active role in drafting regulations for patient workers in hospitals and institutions, under the Fair Labor Standards Act. A suit brought by the American Association on Mental Deficiency and the National Association for Mental Health resulted in a court decision requiring the Department of Labor to enforce minimum wage standards for working patients.

MENTALLY RETARDED OFFENDER

PCMR cosponsored and participated in a symposium on the retarded offender with the University of Oregon Research and Training Center and another under multiple sponsorship held in South Carolina.

Several meetings to discuss resources to serve the retarded offender were called by PCMR and attended by representatives of Office of Youth Development, Office of Human Development, Rehabilitation Services, Developmental Disabilities and Office for Handicapped Individuals.

Different surveys report that from 7 to 32% of the population of correctional institutions are retarded, and that they are given very little rehabilitation or training.

The Committee worked with a Florida State University project on the retarded offender. The project resulted in a grant to FSU from the

Law Enforcement Assistance Administration for four additional regional training conferences on the subject. PCMR staff has also assisted L.E.A.A. in monitoring grants, reviewing proposals, and advising on developing guidelines.

PCMR staff acted as project director for an NARC contract to prepare a police training curriculum that would help law enforcement officers to deal appropriately with retarded persons.

In connection with this project a meeting was held in PCMR's offices with representatives of Florida ARC, the International Chiefs of Police, the Institute for Law Enforcement, the National Association of State Directors of Law Enforcement Training, the Police Foundation, and Developmental Disabilities agencies.

In an effort to see first-hand the environment which spawns so many retarded offenders, PCMR staff toured a high-crime low-income neighborhood with staff of LEAA's Juvenile Justice Council.

The Council's South Bronx Project plus data collected in two other areas could aid in developing methods of prevention and correction.

Committee and staff have held a series of meetings on the retarded offender with key people, including one with the chairman of the Mental Retardation Committee of the National Council of Juvenile Court Judges. This committee is a direct outgrowth of a seminar co-sponsored by PCMR several years ago on retarded youth and law enforcement.

PREVENTION

To coordinate prevention efforts, PCMR members and staff have kept in close touch with the National Institute of Child Health and Human Development, National Institute of Neurological and Communicative Disorders and Stroke, National Institute of Mental Health, Developmental Disabilities Division, and other government as well as private agencies, such as NARC and AAMD.

PCMR's Task Force on Minimum Occurrence of Disability arranged a discussion with the President of the American Medical Association and

"Over half of the deliveries in the University hospital are of young girls less than age 16. Anemia and the stress of growing and the poor diet of the average teenager contribute to make her a high-risk patient in terms of a high-risk infant."

George A. Lentz, Jr., M.D.
Chief, Comprehensive Child Care Program, University of Maryland At Philadelphia Forum

"An estimated 50% of premature infants have some kind of neurological defect, but for babies that weigh below three pounds, the figure can climb to 80%."

Norman Kretchmer, M.D.
Director, NICHD
At PCMR Meeting

JERRY HECHT

Technician opens fertilized chicken egg in tissue culture procedure used in study of neuromuscular disease.

other AMA officials in Chicago to explore ways to prevent retardation and to involve physicians more closely in these efforts. There will be continued cooperation with AMA and PCMR.

Following release of the report of the Governor's Conference on Prevention of Developmental Disabilities, held in California, some Committee members and staff met with the Governor and the State Council on Developmental Disabilities. California has been recognized by the Committee for launching what could be a pilot State program on prevention.

At the request of the Secretary of HEW, who is PCMR's Chairman, PCMR prepared a study on nutrition and mental retardation. It points out the interrelationship between inadequate nourishment and the poor health and low performance often found in poverty areas, but acknowledges the lack of hard scientific data isolating malnutrition as a direct cause of retardation.

PCMR has also consulted with the Chairman of the National Academy of Sciences' Subcommittee on Nutrition, Brain Development and Behavior, who later addressed the full Committee on the subject. The Director of the National Institute of Child Health and Human Development has also discussed nutrition and other aspects of prevention of retardation with Committee and staff.

PUBLIC INFORMATION

Innumerable TV, radio, newspaper, and magazine interviews with Committee members and key staff took place during 1974, in connection with forums, conferences, quarterly PCMR meetings, specific areas of interest of the PCMR work groups, and timely subjects related to mental retardation.

A Gallup Poll commissioned by PCMR in 1974 found that most Americans express accepting attitudes toward retarded citizens as neighbors

---

IMPROVEMENT IN ATTITUDES TOWARD RETARDED PERSONS

Neighbors
1970 48% +
1974 85-95% +

Employees
1970 30.4% +
1974 91.0% +

Institutionalization
1970 11.1%—(i.e., most or all should be in)
1974 1.0%—(i.e., all should be in)

Causes
1970 4.2%—(most or all had retarded parents)
1974 3.0%—(all forms of MR inherited)

Independence
1970 24.1% + (most or all can be self-supporting)
1974 33.0% + (most able to support selves and lead independent lives)

1970: From CEC Research Monograph, "Public Awareness About Mental Retardation," by Henry Gottwald based on national sample of 1,515 subjects.

1974: From Gallup Report prepared for President's Committee on Mental Retardation.

and fellow employees, but some fear and lack of confidence persists.

PCMR's annual report for 1971, *Entering the Era of Human Ecology*, was made into a film by UCLA.

A minority business enterprise produced for PCMR eight radio announcements narrated by Diahann Carroll and played on 400 stations specializing in programs for black audiences. They dealt with prevention of mental retardation.

A series of recorded announcements on legal rights, plus an interview with the Task Force Chairman were distributed to 1500 radio stations.

PCMR also arranged production and distribution of a 30- and 60-second message to all TV networks and 850 TV stations, designed to promote community acceptance.

The National Council on Public Relations, at PCMR's suggestion, devoted a session of its national meeting to winning community acceptance for persons who are mentally restored or retarded. PCMR's Public Information Director chaired the session.

Parents Magazine ran an article by the PCMR Vice Chairperson titled "How All Parents Can Help Our Country's Mentally Retarded Youngsters."

A slide presentation and script on employment of handicapped persons was prepared and distributed to TV stations.

During the Forum held in Philadelphia, the General Manager and Vice President of CBS's WCAU Philadelphia aired a series of three editorials advocating community acceptance of retarded people and supporting a class action suit then pending in the Federal Court of Eastern Pennsylvania to establish group homes in Montgomery County.

PCMR's first film, "A Little Slow" was produced (see p. 21).

A portable exhibit on mental retardation and PCMR's role was completed and has been used at several meetings. PCMR is also preparing a major exhibit for the HEW Bicentennial Exhibit in the South Portal Building, opening in mid 1975.

After the success of the "All in the Family" episode featuring the problems of a young man who was retarded, PCMR presented the producers an award. The suggestion for an episode dealing with mental retardation came from PCMR.

Throughout the year, PCMR has periodically published a newsletter, the *PCMR Message*, and the News Clipping Service. In addition, the following PCMR publications were issued in 1974:

Residential Programming: Position Statements by the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded

MR 73: The Goal Is Freedom (annual report)

Silent Minority (legal rights)

New Neighbors (community living)

Mental Retardation Abstracts (three volumes)

Mental Retardation and the Law (periodical newsletter)

In preparation in 1974:

People Live in Houses (Casebook on alternatives to institutional living)

MR 74 (annual report)

What Are We Waiting For? (report on Early Intervention Conference)

Mental Retardation: The Known and the Unknown (first in Century of Decision series of major report of PCMR)

Mental Retardation: The Century of Decision (Tentative title of PCMR's major report)

"Hear that? That's the future. A black baby taking the first breaths. Singing that old, old song of survival. We know that tune well, you and me. Make sure your child is born with a good body and a good mind. Get yourself vaccinated against German Measles before you get pregnant. This is Diahann Carroll for the President's Committee on Mental Retardation."

"There are many people like me who are in institutions. Today my life is so much better. I am free because I live in a group home. I also have a job that I work at fulltime. It's in the neighborhood and with a big company. They are happy with my work and I am happy there. Because of the group home there are many other people just like me who have jobs. And there could be more. I am told we make excellent, reliable workers. Think about that. I am not living in an institution. Now I have a purpose to my life. I am a happy person."

A resident of Fineson House,
New York City Association for
Retarded Children's Group Home
On 60-second TV spot

"As we approach the 200th anniversary of our nation's existence, let us affirm by our actions that we believe our forefathers' declaration of the rights of all our citizens includes those who happen to be retarded."

N. Lorraine Beebe
Vice-Chairperson, PCMR
Parents Magazine
November, 1974

RECREATION

PCMR participated in conferences on recreation for the handicapped held at the University of New Mexico, George Washington University in D.C., and at the National Forum on Meeting Recreation and Park Needs of Handicapped People in Washington, D.C.

We have also been working with NARC's Recreation Committee in determining their priorities, which are: Stress use of tax-paid recreation; educate the public on the need for recreation as an essential quality of life; deemphasize segregated programs for retarded people; support all positive program developments of public and private organizations.

To reach these same goals, plus integration of services, PCMR has a representative on the Committee on Recreation and Leisure for the Handicapped of the President's Committee on Employment of the Handicapped.

With support from PCMR, NARC is conducting six regional meetings on development of cultural skills for retarded persons.

PCMR has also been active in working with and promoting the "Families Play to Grow" program of the Joseph P. Kennedy Jr. Foundation.

SUPPLEMENTAL SECURITY INCOME

PCMR has been involved in a number of meetings and specially called conferences to attempt to correct the errors affecting retarded people who are being denied SSI benefits because they have been moved to intermediate care facilities, nursing homes, or community housing, or do not appear to fit the stringent eligibility requirements.

The Committee has participated in a series of bi-monthly issue review meetings with SSI staff on the subject, as well as bringing the matter to the further attention of voluntary agencies.

"Paul was a resident of Grafton State School, which is a State institution in North Dakota. Prior to his entrance into the Evaluation and Training Center he was at Grafton for about three years. He is in a hospital now as a result of a bike/car accident. He presently has no funds. The State Social Services Department is in a precarious position in this case because the client is not on SSI and therefore no Medicaid. Who is to pay his medical bills? As of June 12, '74, he was still hospitalized, with further surgical needs. He is now in debt $200 for room and board payments to his landlord."

Mel Heckt
PCMR Member
At PCMR meeting

"The really important point here is that the mentally retarded person is a person, and receives health care under this plan. It's not a matter of whether or not he is retarded, but that he is a person."

Allen Menefee
PCMR Administrative Staff
At PCMR Meeting

TECHNICAL ASSISTANCE AND LIAISON

One of PCMR's major roles is to act as "consultant" to various governmental and private agencies. In 1974, some of the activities involving assistance and liaison included:

Help in planning regional Technical Assistance Program to aid States in applying Intermediate Care Facility Standards;

A series of meetings with national voluntary organizations to consider critical issues in mental retardation;

Assistance in the preparation of the evaluation aspect of Developmental Disabilities legislation;

Initiation of HEW-wide goal for improvement of institutions and reduction of the institutional population;

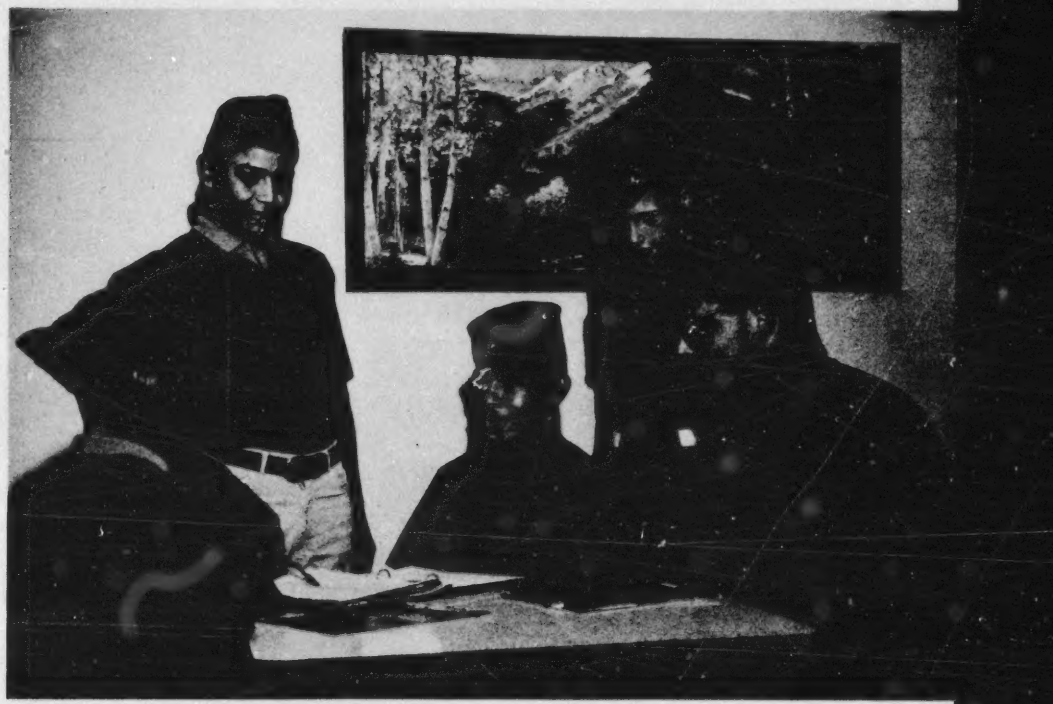
Offered technical assistance to offices of several Governors and Congressmen relative to program planning, quality assurance, standards, etc.;

Discussed with Office of Management and Budget Federal strategies for dealing with mentally retarded people through age 21;

Convened meeting with representatives of HEW agencies and Department of Defense, with each branch of the armed forces represented, to examine present status and a projection of program services for military personnel dependents who are mentally retarded or have related conditions;

Investigated with Office of Child Development plans to deal with child abuse, especially as it relates to children damaged mentally as a result of abuse.

LARRY ROBIN



TRANSPORTATION

PCMR convened a meeting to discuss transportation and the problems it presents for retarded people. Discussion was based on a study done by Auburn University on the subject. Attending were representatives of Department of Transportation, several HEW agencies, United Cerebral Palsy, NARC and Council for Exceptional Children.

YOUTH AFFAIRS

The Committee members and staff have been working with national youth organizations to promote programs involving mentally retarded children and youth. Organizations include: Boy Scouts, Girl Scouts, Boys Clubs of America and Youth-NARC.

NON-TRADITIONAL APPROACHES

In keeping with the orientation to the future of PCMR's major report, the Committee launched a new project in 1974, in search of innovative techniques for aiding retarded individuals.

Specifically, the project is concerned with non-traditional approaches to the diagnosis, treatment, education or training of persons who are retarded. A PCMR staff member is surveying these new concepts to determine their relevance and applicability to mental retardation.

A few of the areas being examined include:

Biofeedback: Electronic instruments used in coordination with the mind to regulate such internal functions as heart rate, blood pressure and brain waves.

Suggestology: Subliminal verbal instruction . . . potentially effective for teaching retarded persons.

Acupuncture: Needles in prescribed parts of the body to alleviate pain.

Parapsychology: The investigation of evidence for telepathy, clairvoyance, and psychokinesis.

Kirlian Photography: Photographing otherwise invisible energy fields surrounding plants and animals . . . being surveyed for possible use in diagnosis.

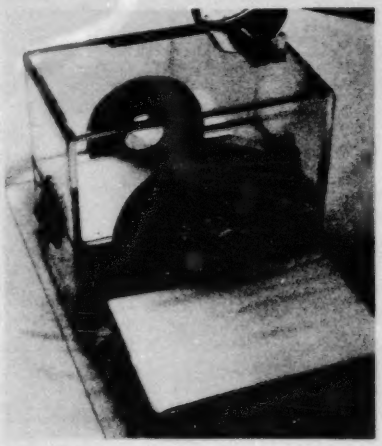
Drugs: . . . Under review as a possible aid in the retention of learning.

PCMR has been in contact with government agencies that are similarly investigating the application of these approaches to alcoholism and mental illness.

Committee representatives have also been meeting with the Technology Utilization Office of the National Aeronautics and Space Administration to explore the application of space technology to treatment for developmentally disabled persons.

"A lot of our parents are poor, and can't afford a car or any kind of transportation. We have no planes, trains, buses, or anything."

Leonard Talaswaima
Impact Worker on Hopi Reservation
At San Francisco Forum



NASA PHOTO

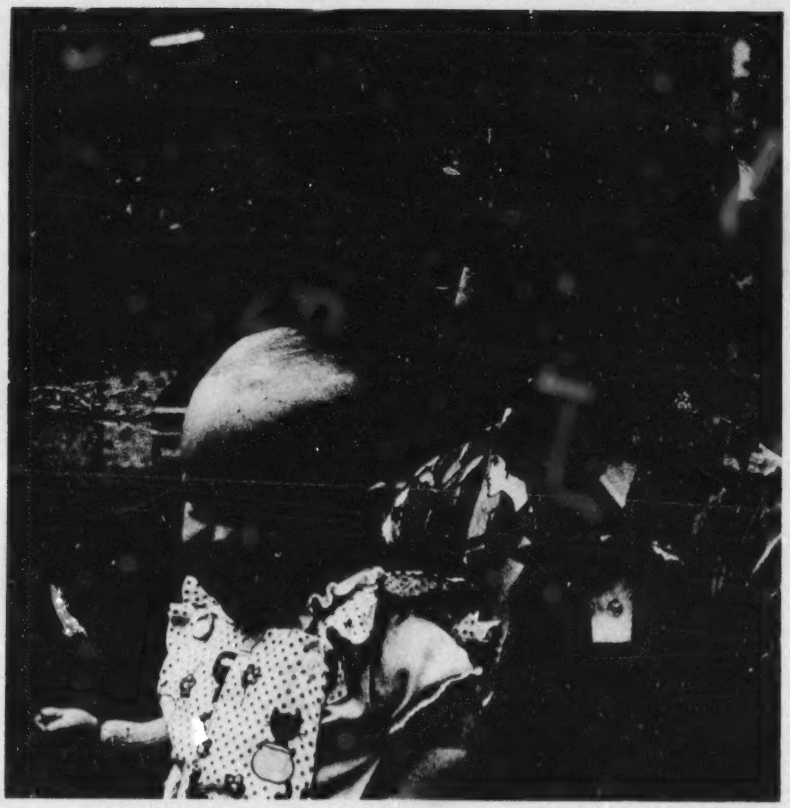
Infant Respiratory Assist Device. The treatment of hyaline membrane disease (respiratory distress syndrome) by medical researchers at the University of Miami is being aided by technology used on-board the NASA SKYLAB. The respiratory assist device is patterned after the lower-body negative-pressure system developed for the SKYLAB program to control the body's distribution in zero gravity.

Down's syndrome children are brought into the Experimental Education Unit of the Univ. of Washington as early as possible for training to bring their developmental patterns as close to "normal" as possible. Presentors: Dr. Alice G. Hayden and Valentine Dmitried of the Child Development and Mental Retardation Center, Univ. of Washington, Seattle.

The infant, toddler and preschool research and intervention project mixes handicapped children with children developing normally in an education program based on Piaget's concepts of human development. Presentors: Drs. Diane and William Bricker, George Peabody College for Teachers, The John F. Kennedy Center, Nashville, Tenn.

A program of educational intervention with high-risk infants is carried out at the Mental Retardation Center, Neuropsychiatric Institute, U.C.L.A. Presentors: Dr. Arthur H. Parmelee and Ethel R. Kass.

EARLY INTERVENTION CONFERENCE



The early intervention program for hearing-impaired infants and young children emphasizes early detection of hearing problems and provides intensive training of parents, especially in helping their children in language and communication skills. Presentor: Kathryn B. Horton of Bill Wilkerson Hearing and Speech Center, Vanderbilt University, School of Medicine, Nashville, Tenn.

In May of 1974, PCMR held a conference on Early Intervention With High-Risk Infants and Young Children. The major emphasis was the "triad" of parents, professionals and the child, working together to help the child either to avoid handicap or to alleviate it.

The conference was co-sponsored by PCMR and the Association for Early Childhood International, with the cooperation and support of the National Institute of Child Health and Human Development, Bureau of Education for the Handicapped, Developmental Disabilities Division, National Institute of Mental Health, Office of Child Development, all of HEW. The University of North Carolina at Chapel Hill was host.

PCMR is publishing a short version of the conference findings in the late summer of 1975. NICHD will publish the papers presented at the conference in the fall of 1975.

The Meeting Street School Parent Program for Developmental Management provides a comprehensive, therapeutic-educational program for children from birth to three years of age. Presentors: Dr. Eric Denhoff and Irma Hyman, Meeting Street School Project, Providence, R.I.

The Portage Project is a model for early childhood education, in which parents are the teachers, trained by a home teacher. The Project serves any child from birth to school age, with any type of handicapping condition, in the 23 school districts of south-central Wisconsin. Presentors: Marsha and David Shearer of Cooperative Educational Service Agency #12, Portage, Wisc.

The National Collaborative Infant Project involves a consortium of centers serving handicapped infants under age two and their families, attempting to identify and use techniques that can be incorporated into service models. Presentor: Una Haynes, United Cerebral Palsy Inc., New York, N.Y.

From "Early Self Help Skills," a manual in the READ Project Series of ten such booklets to help parents instruct their retarded children at home. Presentor: Dr. Bruce L. Baker, Read House, Harvard University.

You will need to find added incentives to draw him into the teaching session, to make him willing to try what you ask.

YOU WILL NEED REWARDS

PROGRAM

1. You start the zipper and zip it up to the middle of your child's chest. Place his/her left hand on the bottom of the zipper to hold it down. Place his right hand on the zipper tab, saying, "Pull up your zipper." Place your hands on his and guide him in zipping up the rest of the way, saying, "Good, you pulled up your zipper," and give him his special treat.

2. You zip the zipper up to the middle of your child's chest. Then, saying, "Pull up your zipper," help him to hold the bottom of the zipper with his left hand. Remove your right hand from his and guide his hand, if needed, in pulling up his zipper. Say, "Good boy, you zipped it up," and give him his special treat.

3. Have him start pulling up the zipper from a couple of inches lower each time he masters a distance. Continue to help him in holding down the bottom of the zipper. Praise him each time he finishes the zipper.

   When he is able to finish zipping all the way from the bottom of the started zipper, start to phase out your assistance in holding the bottom of the zipper (step 4).

4. Have him pull the zipper all the way up with his right hand, but when he is a few inches from the top, remove your left hand from his and say, "Hold on." Have him now finish the zipping without your guidance. Praise him and give him his special treat.

5. Remove your left hand from his hand (which holds the bottom of the zipper) a couple of inches sooner each time until he can do the whole task of zipping - once you have started the zipper - without your assistance. The new task is his.

SUGGESTIONS: When your child can zip up front top zippers without difficulty, begin to work on pant or skirt zippers. Holding and pulling up smaller zippers is more difficult, so it may be necessary to start at step 1 again. In any case, give him clear verbal directions and lots of praise and special treats for each step he masters.

Small Steps

Scott was in tears. He'd certainly tried to get his foot into that pants leg. Only yesterday he'd pulled his pants up with a broad grin - when mother had started them to the knee. But today, she'd just held out the pants for his foot.

Mother realized her error. She was asking too much of Scott in moving too fast, she had brought him to a standstill. She paused and slipped the pants on to just above Scott's ankles.

"Scott, pull up your pants."

The grin again. Success for Scott had once more come easily.

Fears, a tantrum, wandering off - these and many other problem behaviors are not unusual when you are making demands on a child - when you are asking him to do something which you have always done for him. The way to minimize problem behaviors is to keep the task easy.

PCMR FORUMS

"What I heard most was that the government is not reaching the people—in public information and dissemination of information on how to get funding. We seem to be drowning in bureaucratic 'alphabet soup'."

Ralph Ferrara
PCMR Member
At Denver Forum

"I don't think we can separate services from the environment in which they exist."

James A. Pfiffer
State Planning and Developmental Disabilities Council
Hawaii
At San Franciso Forum

"We now have in Oregon a basic system to provide a total delivery of needed services to mentally retarded people . . . starting at birth and going through geriatric services. But no amount of planning or coordinating is going to eliminate the fact that we don't have the funds to serve them. It's that simple."

David Isom
Director of Program Planning
Oregon
At San Francisco Forum

In order to learn first-hand what problems exist and what progress is being made in the mental retardation field throughout the country, the Committee has been holding a series of forums, in cooperation with HEW Regional Offices and the area's Associations for Retarded Citizens.

The information gleaned will contribute to the recommendations made in the PCMR major report, now in preparation.

The first in this current series of forums was held in Kansas City in 1973, covering Kansas, Missouri, Iowa and Nebraska (See *MR 73*).

The 1974 forums were held in Philadelphia, Denver and San Francisco, covering the HEW Regions served by these central offices. Altogether, the forums so far have covered 23 States, Guam, American Samoa and the Trust Territories.

More forums are planned, with the next one to be held in Atlanta in September, covering Region IV.

Major recurring themes throughout all the forums were pleas for a better allocation of funds, especially revenue sharing funds—which were described as "going for bricks and mortar instead of for people"; more training and involvement of the consumer (including people who are retarded) in decision-making and programs; transportation and information. Many also were confused and annoyed by the bureaucratic complexity surrounding government programs that makes them practically unintelligible to workers on the "front lines."

Participants expressed frustration over fragmented services designed to serve a disability or a problem, rather than to serve the whole human being, whose needs are usually interrelated.

Among recommendations to PCMR from the forums on **service systems** were:

Manage the system of services as an orchestration rather than as individual segments. The system's leadership must be responsive to the constituents.

Disseminate information on services more effectively at all levels and avoid bureaucratic "alphabet codes."

Multi-level governmental agencies must be involved with direct services, grants and licensing in coordinated efforts, in order to streamline techniques and develop commonalities in programs.

There should be greater emphasis on generic rather than specialized services, especially in sparsely populated areas.

Make treatments individually appropriate by encouraging agencies to use a cross-section of services.

Utilize existing resources and manpower in the community.

Insist on built-in accountability in services.

"We have a tendency to label people by their uniqueness and not by their needs."

Clarence Evans
Provider of Residential Services
Chester Co., Pa.
At Philadelphia Forum

"We're moving toward revenue sharing, but it's certainly not being shared in services. We must come to multi-based funding and quit depending on the State and Federal Government for everything."

Jack Middleton
Director, Mental Hygiene and Mental Retardation
Nevada
At San Francisco Forum

"We mustn't continue to try to fit children into little pigeonholes in order to get the necessary funds."

L. T. McKnight
Director of Pupil Services
Southeast Delco School District
Delaware Co., Delaware
At Philadelphia Forum

"With only $85 per capita available to provide *all* health services, including environmental health, to our 140,000 people scattered over 3,000,000 square miles, it is difficult to provide optimal medical, educational, and social services to the average citizen, much less to those with handicapping conditions. In summary, we really don't have anything."

Dr. Masauo Kumangai
Director,
Dept. of Health Services
Trust Territory of the Pacific
At San Francisco Forum

Explore and expand attempts to develop interstate planning, such as Virginia and Tennessee have done successfully.

Develop more effective Federal planning, legislation and guidelines to provide models of service, with flexibility and accountability, for application in widely different settings.

Include non-profit, private organizations that can construct and operate community residential programs and facilities.

Encourage community placement when appropriate, but continue to utilize hospital services.

Develop model State zoning laws that could be replicated nationwide.

Funding was of great concern throughout the forums, with many requests for revenue sharing funds to be redirected for the use of people.

Forum recommendations on **funding** included:

Stress money for here-and-now problems and personal services that must be attended to, rather than stressing accountability to the bureaucracy.

Explore stabilized funding of community services, guaranteeing payment for actual costs of services.

Explore use of voucher system to meet client needs and modify the attitudes of providers of services for this system to gain acceptance.

Sort out categorical funding for direct services.

People want better methods of publicizing services and funding; they want a system of sharing solutions to problems; and they want to know how to improve public attitudes toward persons who are retarded and disabled.

Forum recommendations on dissemination of **information** included:

Localize information centers to aid local acceptance and awareness.

Find better methods of publicizing funding available for direct services.

Develop a clearinghouse for obtaining and disseminating new ideas and methods on a national and international basis.

Compile a glossary of key terms and definitions to effect better communications within the developmental disabilities field.

Set up a system of sharing solutions, so that successful programs can be duplicated.

Investigate the use of satellites to disseminate information.

Design public awareness material for specific target groups.

Although there is a need for more exact information on clients, be aware of the danger of computerized data banks, and of how technology can depersonalize and threaten client confidentiality.

Involvement of mentally retarded persons and their parents also came in for a large share of recommendations by the forum participants.

Included in the forums' recommendations on **"consumers"** were:

Include mentally retarded people as much as possible in decision making that affects their lives.

Encourage conferences sponsored by retarded persons for themselves.

De-emphasize labels traditionally given to children who are retarded. Treat each person as an individual.

For more effective training, involve the University Affiliated Facilities more directly with the community, especially with parents and consumers.

Include input from parents when Federal and State bureaucracies design programs, so that there will be a more humane approach to services.

In defining educational needs, there was emphasis on early childhood, and changing concepts of when the re-

LARRY ROBIN

"When we ask whether or not the delivery system is accredited, the ultimate criterion really is: What has happened to the people who are being served?"

Dr. Henry Cobb
PCMR Member
At Denver Forum

LARRY ROBIN

"In the Asian community there is a strong cultural stigma against abnormalities. Rather than seeking help, the families would rather hide in a closet—just as they did here in America 50 years ago."

Reiko Homma True
Consultant to Asian Community MH Service
Alameda County, California
At San Francisco Forum

"A recurring concern that really touches on all of the major areas discussed here was the plea for additional help for parents of disabled persons. We are in tremendous need for very specialized counseling and training services for parents. We must begin to recognize the parents' individual needs, and we must begin to deal with the family as a family and not as a series of individuals."

Thomas Scheinost
Director, Div. MH/MR
South Dakota
At Denver Forum

"The existing standard tests of intelligence are biased against black children."

Dr. Harold Dent
S.F. Bay Area Assn. of Black Psychologists
At San Francisco Forum

sponsibility to educate children begins. Equal educational opportunity for all children was also high on the list of priorities.

Among the **education** recommendations of the forums were:

Introduce legislation to extend the responsibility of educational systems to infants.

Expand successful early childhood stimulation programs.

Determine what techniques in education are working well.

Provide adequate resources to implement "right to education" court decisions.

Education must be as available to mentally retarded and developmentally disabled individuals at all age levels as it is to others.

Forum participants focused on better training of both professionals and paraprofessionals as one of the solutions to the manpower problem.

Among the forums' recommendations on **manpower** were:

Study specific manpower needs so that effective skills and competencies can be taught.

Retrain professionals who are not current with modern developmental disabilities treatment techniques.

Sensitize paraprofessionals and physicians particularly to the problems in the developmental disabilities area.

Train county Public Health nurses and county Extension Service agents (under Dept. of Agriculture) to provide early screening, diagnosis and evaluation, especially in rural areas.

Representing Indian interests at the Denver Forum are (l to r) Mrs. Gayla Twiss, Pine Ridge, S.D., and Mrs. Claudette Janis, Rosebud, S.D.

There was interest in providing better and increased prevention measures of a wide variety.

Included among the forum recommendations for **prevention** were:

Develop and implement more early screening, identification, diagnostic and evaluation clinics and resources for early intervention, particularly in rural areas which lack facilities and transportation.

Encourage education for parenthood. Develop courses in child development for junior and senior high school students, including experience in community child-care centers. Include courses in handicapping conditions.

Teach students the importance of good nutrition, and pre- and post-natal care, plus knowledge o. community service systems.

Educate mothers to nutritional needs, especially in densely populated, poverty areas, where the incidence of mental retardation is high.

Use the Public Health model, oriented to prevention, in the delivery of services.

Make available more pre-parent counseling, parent counseling and genetic counseling.

The following additional recommendations were offered by the forums' members:

Look to the private sector as well as to government for vital, innovative contributions to the field of mental retardation.

Adopt model programs of citizen advocacy more widely.

Encourage a continuum of comprehensive programs of basic research, research and demonstration, and program evaluation research.

Coordinate programs of the Bureau of Indian Affairs and the Indian Health Service; and settle the question of Federal vs. State vs. local jurisdictions on Indian reservations.

As 1974 came to a close, the bulk of the massive research on the material for the projected major report to the President and to the nation, *Century of Decision*, had been completed. The report will be a blueprint for progress in the mental retardation field.

As long as babies continue to be born handicapped by mental retardation, as long as those with such a handicap are disabled, as long as people who are retarded are dehumanized, ignored, discriminated against, the President's Committee on Mental Retardation will have a mandate for action.

Dr. John Meier

"Jurisdictional problems are tremendous. We have to deal with the Federal Government's Bureau of Indian Affairs and Public Health Service Indian Health Service; State, regional, county, local and tribal jurisdictions. Health services are very much geared to acute illness. We are very poor in prevention. There is an urgent need for transportation. Our strength is in the parents, and they want to get involved, but they are handicapped by vast distances and lack of transportation."

Miss Sophie Thompson
PHS/Indian Health Service
Navajo Nation, Arizona
At San Francisco Forum

"An increasing number of young girls are bearing children. They're not ready physiologically, economically, psychologically or emotionally. It takes a great deal to be ready for this most important task of life."

"We insist that a person have a license to drive a car, to run a day-care center, to operate a restaurant or hotel, to fish or hunt—and have no provision for basic competence in parenthood. Minimum occurrence of disability might be minimized even further if there were some way of controlling or improving the competence of mothers and fathers."

Dr. John Meier
Director, John F. Kennedy
Child Development Center
U. of Colorado, Denver
At San Francisco Forum

"People in the medical profession, and even those in psychology and social work are very well versed on diagnosis and causation, but are limited in their knowledge of how children learn. Diagnosis is excellent; prescription very low."

Dr. Dan Payne
Asst. Commissioner
Program Development and Eval.
Virginia Dept. of MH/MR
At Philadelphia Forum

"Perhaps regionalization is working too well; there is little consistency in delivery of services in child development centers. It depends upon the professional orientation of the program directors."

Steven Anderson
Administrative Assistant
Idaho State School and Hospital
At San Francisco Forum

"It's been approximately five years since I stood before a group talking about mental retardation. When I left for Africa five years ago I had the feeling that the retarded person was being fragmented. Now I sense that whole groups are talking about whole people. We are putting the retarded person back together again. Together, we can do the job. But alone, it will be the fragmented person as it started out to be."

George Jones
Ex-PCMR Member
At Denver Forum

JULES SCHICK

THE PRESIDENT'S COMMITTEE ON MENTAL RETARDATION 1974

Hon. Caspar W. Weinberger
Washington, D.C.

Chairman, PCMR; Secretary, U.S. Dept. of Health, Education, and Welfare.

Mrs. N. Lorraine Beebe
Dearborn, Mich.

Vice Chairman, PCMR

Previous Experience: Executive Director, Michigan Consumers Council; State Senator; teacher, counselor, Michigan Public Schools.

M.S. Clinical Psychology, Univ. of Michigan

Ex-Officio Members:
The Attorney General of the United States

The Secretary of Labor

The Secretary of Housing and Urban Development

The Director, Office of Economic Opportunity

The Director, ACTION

Mrs. Marianna Beach
Hays, Kans.

Board of Directors: Kans. Assn. for Mental Health, Hays Day Care Center for Exceptional Children, Homer B. Reed Adjustment and Training Center; Ex-Officio Member: Advisory Council on Special Education, Kansas State Board of Education.

B. S., Industrial Journalism, Kansas State Univ.

Dr. Henry VanZandt Cobb
Chapel Hill, N.C.

Editor: PCMR's major report

Previous Experience: Vice President, Acting Dean of Graduate School, Professor, Univ. S.D.; President, International League of Societies for the Mentally Handicapped; President, NARC; Visiting Professor, Psychology and Education, Teachers College, Columbia Univ.

Ph.D., Philosophy, Yale Univ.

Robert A. Collier
Alexandria, Va.

Senior Partner, Collier, Shannon, Rill and Edwards, Washington, D.C. law firm; Chairman of the Board, Macmillan Ring-Free Oil Co., Inc.

Previous Experience: Legal counsel, U.S. Senate and House Committees.

LL.B, Univ. of Texas

Frank R. DeLuca‡
Charleroi, Penna.

Business Manager, Plummers and Pipefitters Local 354, Latrobe, Pa.

Previous Experience: President, Pa. State Building and Construction Trades Council; Board of Directors, Monongahela Valley Industrial Development Commission; Chairman, March of Dimes, Washington County, Pa.

Richard J. Elkus
Woodside, Calif.

Chairman of the Board, Ampex Corp., Redwood City, Calif.; Board of Directors, Mercantile Credit Co., London, England.

Previous Experience: Chairman of the Board, U. S. Leasing Corp., San Francisco; Board of Directors, Mental Health Research Institute and Children's Health Council, San Francisco.

Ralph J. Ferrara
Kinnelon, N.J.

Director, College Development, Montclair State College, Upper Monclair, N.J.

Previous Experience: Special Assistant to the Chancellor, N.J. Dept. of Higher Education; Director of Alumni Affairs, Fairleigh Dickinson Univ.; Board of Directors, American Institute of Mental Studies, Vineland, N.J.; special education teacher, Hoboken Public Schools.

M.A., Special Education, New Jersey State College; Maxwell House Graduate Fellow.

Michael R. Gardner
Washington, D.C.

Deputy Assistant Administrator for Energy Resource Development, FEA; 3rd year student, Georgetown Law Center.

Previous Experience: Michael R. Gardner & Assoc.; Public Relations; Special Assistant to John B. Connally; Public Affairs, Office of Economic Opportunity.

B.A. Political History, Georgetown Univ.

Melvin D. Heckt
Minneapolis, Minn.

Vice President, Richards, Montgomery, Cobb and Bassford, Minneapolis law firm; Member, Board of Directors and Regional Vice President, NARC.

Previous Experience: President, Minnesota and Minneapolis ARC.

J.D. Univ. of Iowa.

Dr. Cecil B. Jacobson†
McLean, Va.

Director, Reproductive Genetics Unit, The George Washington Univ. Medical Center.

Previous Experience: Macy Foundation Faculty Fellow in Obstetrics, The George Washington Univ.

M.D., The George Washington Univ.

James N. Juliana †
Rockville, Md.

President James N. Juliana Associates, Inc., Washington, D.C., management and public affairs consultant firm.

Previous experience: Special Agent, FBI; Chief Counsel and Minority Counsel, Senate Permanent Subcommittee on Investigations; Executive Director, Civil Aeronautics Board.

B.S., Washington College, Chestertown, Md.

Lawrence A. Kane, Jr.
Cincinnati, Ohio

Partner, Dinsmore, Shohl, Coates and Deupree, Cincinnati law firm; Member of the Board, National Center for Law and the Handicapped, Notre Dame, Ind.; President and Chairman of the Board, Resident Home for the Mentally Retarded of Hamilton County, Ohio.

Previous Experience: Co-chairman, American Bar Assn., Subsection Mental Retardation, Law and Ethics.

J.D., Notre Dame Law School.

Aris A. (Bob) Mallas †
Austin, Texas

President, Management Services Associates, Inc., and an officer and Director of 14 other companies.

Previous Experience: Member, National Advisory Board, NARC; Member of Board of Trustees, Commission on Accreditation of Rehabilitation Facilities; Director, Goodwill Industries, Austin; Founder, Austin Community Council; Director, major research studies of government programs.

M.P.A., Wayne University, Detroit; Volker Fellow; Advanced studies, Univ. of Heidelberg, Germany.

Hon. Thomas J. Meskill *
Hartford, Conn.

Judge of the U. S. Court of Appeals

Previous Experience: Governor, State of Connecticut; U. S. Congressman; President, New Britain Council of Social Agencies

LL.B., Univ. of Connecticut

* Resigned after Judicial appointment

Lloyd E. Rader
Oklahoma City, Okla.

Director, Oklahoma Dept. of Institutions, Social and Rehabilitative Services; Executive Council, State Welfare Directors and Administrators.

LL.B., Oklahoma City Univ.

Mrs. Louise R. Ravenel
Charleston, S.C.

Secretary, S.C. Developmental Disabilities Council, Chairman of Priorities Committee, and Chairman of Special Subcommittee on Retarded Offender; Member, S.C. Governor's Committee on Mental Health and Mental Retardation; Member, NARC Legal Advocacy Committee; Member, Advisory Committee of Southeastern Management Training Project, Univ. Alabama; Chairman, S.C. Interagency Task Force for the Retarded Offender.

Previous Experience: Member, NARC Governmental Affairs Committee.

College of Charleston, S.C.

William B. Robertson
Washington, D.C.

Director, Consumer Affairs Office, District of Columbia.

Previous Experience: Special Assistant to Governor of Virginia, Linwood Holton, for Minority and Consumer Affairs; Assistant Director for Programs, Extension Div., Va. Polytechnic Institute and State U., Blacksburg, Va.; teacher, principal, supervisor, Roanoke Public Schools.

M.S., Administration, Radford College

Kenneth S. Robinson ‡
Nashville, Tenn.

Student, Harvard Univ., Biology

Previous Experience: President, Youth-NARC.

Dr. Will Beth Stephens †
Dallas, Texas

Professor and Program Chairman of Special Education, Univ. of Texas at Dallas.

Previous Experience: Professor of Special Education, Temple Univ., Philadelphia; Professor, Univ. of Illinois and Univ. of Texas.

Ph.D., Educational Psychology, Univ. of Texas; Post-doctoral study, Univ. of Geneva, Switzerland.

Margaret B. Ulle †
Baltimore, Md.

Member, Maryland Advisory Council on Developmental Disabilities.

Previous Experience: Chairman, Governmental Affairs Committee, NARC; President, Maryland ARC; Vice President, NARC Northeast Region; Member, President's Task Force on the Mentally Handicapped.

A.B., Randolph-Macon Woman's College.

Dr. Miriam G. Wilson
Los Angeles, Calif.

Chief, Genetics Div., Los Angeles County-Univ. of Southern California Medical Center; Professor of Pediatrics, U.S.C. School of Medicine; Director, Human Cytogenetics Laboratory for Training and Research, L.A. County-U.S.C. Medical Center; Member, State Areawide Developmental Disabilities Program Board #10

M.D., Univ. of California, San Francisco

† Reappointed for three-year term
‡ Term expired Oct. 23, 1974

Appointed October 23, 1974

Dr. Geraldine M. Clark
Bountiful, Utah

Director, Office of Child Development, State of Utah.

Previous Experience: Specialist, Programs for the Mentally Retarded, Utah State Board of Education; Assistant Coordinator, Interagency Coordinating Council for Mental Retardation, State of Utah; Chief Audiologist, Salt Lake City Schools.

Ph.D., Educational Psychology, Brigham Young Univ.

Dr. Bill J. Doggett
Clinton, S.C.

Superintendent, Whitten Village, Clinton, S.C.

Previous Experience: Deputy Commissioner for Mental Retardation Services, Texas Dept. of Mental Health and Mental Retardation; Superintendent: Brownwood State Home and School for Girls; Statewide Reception Center for Girls; Austin State School, Travis State School.

M.Ed., Educational Administration, Univ. of Texas. Honorary Doctor of Humanities, Howard Payne College, Brownwood, Tex.

Dr. Philip U. Martinez
Albuquerque, N.M.
Neuro-surgeon

Previous Experience: Neurological surgery, Veterans Admin. Hospital, Long Beach, Calif.; General surgery, Albert Einstein Medical Center, Southern Division, Philadelphia, Pa.

M.D., Univ. of Colorado.

PCMR STAFF (At publication date)

Office of the Director

Fred J. Krause
Executive Director

Stanley J. Phillips
Special Assistant
Gwendolyn R. Coleman

Program Office

Allen R. Menefee
Assistant Director, Program

Alfred D. Buchmueller
Bertha F. Kaminker
Jack McAllister
Miles Santamour
Mary Frances Smith
William H. Wilsnack
Jacqueline L. Mordecai
Ruth H. Seymann
Pierrette Spiegler

Information Office

Raymond W. Nathan
Assistant Director, Communications

Martin Bouhan
Mary Z. Gray
Nancy O. Borders
Beverly M. Keith
Mattie A. Smith

Management Office

Fay L. Whitcup
Larry Lane

Consultants—1974

Harold S. Barbour, Ed.D.
Leo F. Cain, Ph.D.
Julius S. Cohen, Ed.D.
Louis Z. Cooper, M.D.
Ross H. Copeland
Patrick J. Doyle, M.D.
Maurice Flagg
Erwin Friedman, Ph.D.
Dennis E. Haggerty, LL.B.
Edward L. Johnstone
Arthur J. Nowak, D.M.D.
Paul A. Rittmanic, Ph.D.
George Tarjan, M.D.
John D. Thompson, M.D.
Thomas A. Tucker